

2-25-15

To: Government Administrations and Elections Committee

Re.: H.B. #6100 "An Act Designating a Spinal Muscular Atrophy with Respiratory Distress Awareness Day"

From: Sharon Agli-Pageau, Hunter Pageau, North Haven, CT

SHARON: Thank you so very much, Senator Cassano, Representative Jutila, Senator McLachlan, Representative Smith and the entire committee. SMARD is a virtually unknown and invisible rare disease, both in the medical community and our State communities, at large. We are here today to strongly advocate for your support of House Bill 6100, An Act Designating a SMARD Awareness Day. It is only with your respected support, as our State Leaders, that the possibility for the very much needed awareness for SMARD can occur on the State level. Your support will further our decade long efforts to remove the extreme isolation and lessen the profound hardships faced by SMARD families, due to the Orphan disease status, as designated by the National Organization for Rare Diseases. We are the face of SMARD, we are mostly alone and we are kindly asking to be "adopted," per se, by our home state, via the passing of House Bill 6100. I'd like to introduce my amazing son, Hunter, whom is a true pioneer of SMARD.

HUNTER: February is the month of Love, and Rare Disease Awareness Month. I have a very rare disease called Spinal Muscular Atrophy with Respiratory Distress. An easier way to say that is S-M-A-R-D. There are only 10 people in the United States and 80 worldwide with this disease. Despite the many challenges I face because of the outstanding rarity of my disease, I always do my best. I am at the top of my 4th grade class and a Student Council Leader. I do not let my disease discourage me from being happy or following my heart and my dreams. SMARD is not who I am. It is only a part of me, but not all of me.

I'd like for you to take a minute to imagine what your life would be like if you had a rare disease, if the world was just in the beginning stages

of learning about it? I bet you would want others to love and support you with all of the hardships you'd face, believe in you, encourage you, and stand beside you on your journey. No one should ever have to be alone when battling a rare disease. The love and support that you share can make all the difference.

I am honored for every opportunity to share RARE, which to me is an acronym for "raise awareness for research and education" of rare diseases, like mine, and to be the voice of Hope. Those with rare diseases often face extreme struggles, because there is so little known about their disease, or cures found yet. I am wanting and hoping to make a true difference for those with SMARD because I know how extra challenging everyday life can be and how important it is to have compassionate support from others. I shared my hopes with State Representative Yaccarino and Senator Fasano, whom also believe firmly in the importance of raising SMARD awareness, with hopes of moving closer to better treatment and research for a cure.

I will be 10 years old this year. I would like nothing more than to achieve my long term goal of raising SMARD awareness in Connecticut. Will you please join me to make the next decade full of opportunities that are not there for me right now, due to SMARD being an unknown disease? I need your help for a better life, an equal life to those of my friends, but I can't achieve this without you. I will continue to be hopeful. I am very grateful for your support. Thank you.

Most Sincerely,

Sharon Agli-Pageau
Hunter Pageau
North Haven, CT
(203) 627-3948